

SOCIAL NETWORK SITES AS INFORMATIONAL
SOURCES IN SURROGATE DECISION-MAKING

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Much has been said on the proposed use of social network sites (SNS) as informational sources in the surrogate decision-making process. Since it was suggested by Jessica Berg in her article, "Surrogate Decision Making in the Internet Age," there has been a flurry of scholarly commentary debating the value of such information; considering the practicality and feasibility of its use; determining the myriad of ways social network sites could be involved in medical decision-making; and teasing out the possible moral concerns that arise out of the inclusion of information gleaned from SNS¹. This project critically analyzes the benefits and possible hazards of using social network profiles as informational sources for surrogate decision-making and outlines a framework within which one can evaluate the situational applicability of its use. Ultimately, I argue that in certain cases SNS are an appropriate and helpful informational source for use in surrogate decision-making. Furthermore, I argue that the information retrieved from SNS sites ought to be evaluated and considered in much the same way that other, more traditional sources of information are evaluated: for legitimacy, cogency, relevance, authenticity.. I discuss the clinical implementation of efforts to employ SNS in the decision-making process and the dilemma that this new endeavor may create. I also discuss possibilities for future research into the practice of using SNS as informational sources for surrogate decision-making.

¹ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 28-33.

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PREFACE

I am deeply grateful for the guidance, wisdom and support I have received from my thesis advisor, Alan Meisel. Alan has patiently worked with me on the development of this project for some time and has been a great resource and mentor to me. I am greatly indebted to him. I am thankful to my thesis committee members, Mark Wicclair and John Lyne for their careful evaluation of my writing and helpful suggestions, which have produced a superior project. I thank Lisa Parker who has been a great help to me in my progression through the MA program in bioethics. It was in her course that I came upon the idea that would later become the topic of this project. I am truly grateful for her guidance and direction, both personal and professional over the last several years.

I am so thankful to my parents for their support and encouragement. It has meant so much to me. And to my love, Scott, our friendship has been the most transformative experience of my life. Your encouragement, graciousness and kindness have been my strength. I am forever grateful.

“In normal life we hardly realize how much more we receive than we give, and life cannot be rich without such gratitude. It is so easy to overestimate the importance of our own achievements compared with what we owe to the help of others.”

— Dietrich Bonhoeffer, *Letters and Papers from Prison*

1.0 INTRODUCTION

Much has been said on the proposed use of social network sites (SNS) as informational sources in the surrogate decision-making process. Since it was suggested by Jessica Berg in her article, “Surrogate Decision Making in the Internet Age,” there has been a flurry of scholarly commentary debating the value of such information; considering the practicality and feasibility of its use; determining the myriad of ways social network sites could be involved in medical decision-making; and teasing out the possible moral concerns that arise out of the inclusion of information gleaned from SNS.² This project critically analyzes the benefits and possible hazards of using social network profiles as informational sources for surrogate decision-making and outlines a framework within which one can evaluate the situational applicability of their use. First, I provide a working knowledge of social network sites, background information on the philosophical foundations for surrogate decision-making, and a summary of existing literature on the use of SNS as informational sources for surrogate decision-making. Second, I outline scenarios where the use of SNS as informational sources for surrogate decision-making may be relevant and appropriate. This helps to develop an understanding of the range of circumstances

² Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 28-33.

where such information may be most helpful, as opposed to merely additional, possibly confusing, information concerning the subject. Third, I elucidate potential scenarios for using SNS as informational sources for surrogate decision-making, where employing such information may be either useless or detrimental to the decision-making process. I discuss the clinical implementation of efforts to employ SNS in the decision-making process and the dilemma that this new endeavor may create. I also discuss possibilities for future research into the practice of using SNS as informational sources for surrogate decision-making.

In the first chapter, I provide a background on SNS, how they originated, and the type and prevalence of their use. I then discuss surrogate decision-making, how an appropriate surrogate is appointed, by what standards surrogates are to make their decisions, and how the decision-making process will occur. I also include a brief discussion of more common sources of information for surrogates, other than SNS, that might be relevant to the decision-making process. This discussion serves as segue for the suggestion that social network profiles may act as valuable informational sources for surrogate decision-making. The first chapter acts as a foundation to contextualize the latter two. To conclude the opening chapter, I provide a review of the current academic literature surrounding the use of SNS as informational sources for surrogate decision-making.

In the second chapter, I elaborate on how SNS may provide valuable information for surrogate decision-making, specifically addressing scenarios in which I suggest that SNS profiles may be of use, as tools for determination of, or informational sources for surrogates, and in conflict resolution. This section provides a contextual framework to categorize situations as appropriate or inappropriate for the inclusion of information from SNS in the surrogate decision-making process. In the third chapter, I address possible hazards and helpful cautions to consider

when approaching the use of SNS as informational sources for surrogate decision-making. This section provides a complementary contextual framework to categorize situations which may be unaffected, or negatively affected by the attempted use of SNS as informational sources for surrogate decision-making. This chapter also addresses the difficulty of the application of such an endeavor for the clinical environment. At this time, it is unclear who might be responsible for the retrieval of SNS information in a clinical setting, who might be responsible for determining the appropriateness and relevance of that information, or how the clinical team or family may come into possession of the patient's SNS profile.

Though SNS as informational sources for surrogate decision-making has been discussed at length in recent literature, this project is different in a number of ways.^{3,4,5,6,7} First, this project comes out of, and will include, an explicit discussion of the philosophical foundations of surrogate decision-making. The argument for the consideration of the information found on SNS profiles directly relies on some basic principles of surrogate decision-making, such as the value of self-determination, the substituted judgment standard, and non-maleficence—something not explicitly addressed in other arguments in favor of using SNS as an informational source.

³ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 28-33.

⁴ Moore, Jessica A., and Colleen M. Gallagher. "Are We Prepared for Surrogate Decision Making in the Internet Age?" *American Journal of Bioethics* 12.10 (2012): 47-49.

⁵ Siess, Samantha, and Anne Moyer. "Status Update: The Complexities of the Internet Age Bring Urgency for Deliberately Making Advance Health Care Wishes Known." *American Journal of Bioethics* 12.10 (2012): 49-50.

⁶ Pope, Thaddeus Mason. "Facebook Can Improve Surrogate Decision Making." *American Journal of Bioethics* 12.10 (2012): 43-45.

⁷ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

Second, this project addresses broader parameters and scenarios than current literature suggests, within which the use of information from SNS may be useful. The scenarios are meant to provide a framework for categorizing situations in terms of a fourfold classification scheme of applicability for the use of SNS information in the medical decision-making process. The four categories are, “clearly relevant,” “possibly relevant,” “possibly irrelevant,” and “clearly irrelevant.” This framework acknowledges and supports the existing ideas in favor of, and in disagreement with the use of SNS profiles, with the hope that there might be recognition that this informational source has value, but that value may be limited to specific situations and should be subject to certain constraints. These constraints may include examination of the reliability and consistency of the information recovered, as well as the timeframe and state of mind in which the material was produced.

1.1 SOCIAL NETWORKING SITES

According to an article in the *Journal of Computer-Mediated Communication*, social network sites are defined as “web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system.”⁸ In 1997 the first social network site, SixDegrees.com, began by allowing users to

⁸ Boyd, D. M., Ellison, N. B. (2007) Social Network Sites: Definition, History and Scholarship. *Journal of Computer-Mediated Communication*, 13 (1), article 11. Web.

create personal profiles that were visible within the online database. Since their inception in 1997, hundreds, perhaps even thousands, of social network sites (SNS) have been established, most notably, Myspace in 2002, Facebook in 2005, and Twitter in 2006.⁹ *BusinessWeek* reports that in 2005, Myspace boasted over 40 million users. In November of 2009, Twitter reported approximately 23 million users per month, and in December of 2009, Facebook reported that it had over 350 million active users.^{10,11,12} By 2012, those numbers had radically changed, with Myspace reporting approximately 5 million daily visitors, Twitter reporting 500 million users, and Facebook reporting over 1 billion users worldwide, a staggering one-seventh of the global population.^{13,14,15} According to a 2011 Pew Research Center study, *Social Networking Sites and Our Lives*, “79% of American adults said they used the internet and nearly half of adults (47%), or 59% of internet users, say they use at least one SNS. This is close to double the 26% of adults (34% of internet users) who used a SNS in 2008.”¹⁶ As evidence shows, online social network

⁹ Boyd, D. M., Ellison, N. B. (2007) Social Network Sites: Definition, History and Scholarship. *Journal of Computer-Mediated Communication*, 13 (1), article 11. Web.

¹⁰ Hempel, J., Lehman, P. "The Myspace Generation." *BusinessWeek*. BusinessWeek Magazine, 12 Dec. 2005. Web.

¹¹ "Data overview for twitter.com." Twitter.com UVs for December 2009. Compete, n.d. Web. 19 Dec. 2009.

¹² "Facebook Asks More Than 350 Million Users Around the World To Personalize Their Privacy." Facebook Newsroom. N.p., 9 Dec. 2009. Web. 19 Dec. 2009.

¹³ "Ad Planner." *Google Display Network*. Google, n.d. Web. 1 Mar. 2013.

¹⁴ Lunden, Ingrid. "Analyst: Twitter Passed 500M Users In June 2012, 140M Of Them In US; Jakarta 'Biggest Tweeting' City." *TechCrunch RSS*. N.p., 30 July 2012. Web. 1 Mar. 2013.

¹⁵ Vance, Ashlee. "Facebook: The Making of 1 Billion Users." *BloombergBusinessweek.com*. Bloomberg Businessweek, Technology, 4 Oct. 2012. Web. 8 Jan. 2013.

¹⁶ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013.

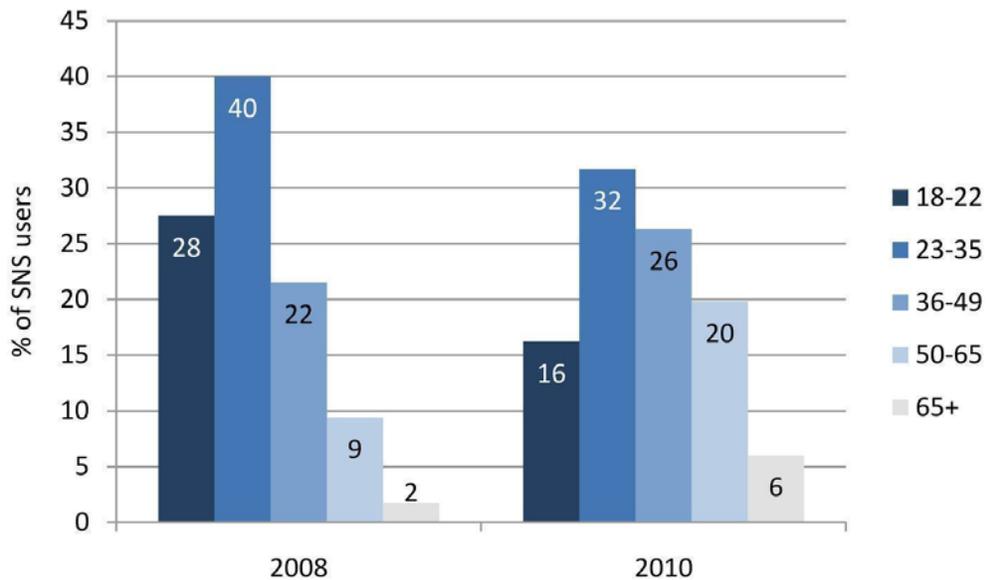
use has largely caught on and greatly increased over the last seventeen years, since the earliest sites in 1997. Furthermore, it is notable that the demographic of those using SNS has changed, and the average SNS user has shifted from 33 to 38 since 2008.¹⁷ This is particularly relevant as SNS use has changed from a service considered to be primarily targeted toward children and young collegiate adults, to something that is used primarily by older adults—even into their middle age (See Figure 1¹⁸).

¹⁷ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013.

¹⁸ *Ibid.*

Age distribution of social networking site users in 2008 and 2010

% of social networking site users in each age group. For instance, in 2008, 28% of social networking sites users were 18-22, but in 2010 that age group made up 16% of social networking site users.



Source: Pew Research Center's Internet & American Life Social Network Site survey conducted on landline and cell phone between October 20-November 28, 2010. N for full sample is 2,255 and margin of error is +/- 2.3 percentage points. N for social network site and Twitter users is 975 and margin of error is +/- 3.5 percentage points.

Figure 1 Age distribution of social networking users in 2008 and 2010¹⁹

Upon registering to be a part of a social network, new users are often asked to answer a series of questions, usually concerning gender, age, place of birth, residence, and hobbies, and are encouraged to include additional personal information that they would like to share. Many

¹⁹ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013

sites also allow and even prompt users to include personal pictures on their profiles and permit the inclusion of other “applications” such as personal blogs, private or public notes, video, and link sharing. Depending on the site’s privacy policies, users are commonly allowed to restrict the viewing access of their personal profiles or certain information contained in their profiles. For instance, some users may choose to keep their profiles open so that they might be viewed in full by anyone who searches within the social network site or even through a common online search engine. Others, however, might restrict their profile visibility to approved social contacts or even to specific individuals in their approved contact list. Nonetheless, despite the ability to restrict access to personal information, many social network users choose to allow their information to be visible to a wider audience than merely approved contacts. This is often the default. The display of an individual’s personal connections is a defining feature of social network sites—the point of which is to encourage users to find and “add” additional contacts. Moreover, most social network sites afford users the ability to message within the network, both privately (much like email) and publicly, as a post or “comment.” Most posts and comments continue to be visible on the profile and can be viewed by any approved contacts.²⁰

Most recently, interactive additions have been incorporated into the social network arena. Many of these features are being built into the experience by various plug-ins and social add-ons. As an example, these include the ability to “like” publications and websites from outside Facebook’s website, share images, posts and feeds on other social network sites, and use social network site login credentials—and all associated data—to access third-party services and

²⁰ Boyd, D. M., and N. B. Ellison. "Social Network Sites: Definition, History and Scholarship." *Journal of Computer-Mediated Communication* 13.1 (2007): n. pag. Web.

websites, including games and retail purchasing. However, some of the most important and innovative uses of social network sites are being developed as part of the core experience. In 2010, Facebook introduced advanced facial recognition technology, allowing automatic detection of friends and contacts in one's photos. In 2011 Facebook automatically enabled the feature by default for all current and new users.²¹ In May 2012, the social network site announced that it would begin encouraging its then 161 million users in the United States to publicly declare their organ donation status within their profiles and included instructions on how to register online and with state and local authorities.²² By September 2012, it was reported that 275,000 users had posted their organ donation status on the site.²³

Unlike what their name seems to imply, social network sites are often not used in the hope of "networking" or making connections with people who would otherwise be merely strangers. In fact, it is reported that *very* few contacts in one's Facebook profile are "strangers." A mere 7% of the average Facebook user's contacts, or "friends," are those whom the user has never met in-person and only 3% of contacts have been met in-person only one time.²⁴ In 2011, the Pew Research Center found that, "the average user of a social network site has more close

²¹ Bilton, Nick, "Facebook Changes Privacy Settings to Enable Facial Recognition," *The New York Times Bits Blog*. New York Times, 7 June 2011. Web. 26 Mar. 2013.

²² Richtel, Matt, "Facebook is Urging Members to Add Organ Donor Status," *The New York Times*. 1 May 2012. Web. 26 Mar. 2013.

²³ Schulz, David, "The 'Facebook Effect' on Organ Donation," Shots. NPR, 20 Sep. 2012. Web. 26 Mar. 2013

²⁴ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013.

ties and is half as likely to be socially isolated as the average American.”²⁵ According to various studies and articles supporting this claim, the goal of social network users is often to become more knowledgeable about people with whom they have offline interpersonal connections.²⁶ Studies conducted at Michigan State University concerning Facebook in particular have led researchers to believe that connections are made primarily to enrich or maintain offline connections.²⁷ In 2011, this claim was broadened to include all SNS, affirming previous data that connections on SNS are used largely in order to enrich existing (outside) social relationships.²⁸ Another interesting finding from these studies is that the Facebook users “reported high confidence” (mean response of 4.16 out of a possible scale of 5) that the information contained on their profiles created an accurate representation of their personal values and worldview.²⁹ This point is significant in understanding the role that social network sites and personal user profiles have on societal and cultural understandings of what they are and how we use them. Social networking profiles are founded on the idea that you put a little piece of your (authentic) individuality out in the open to share with the world.

²⁵ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013.

²⁶ Boyd, D. M., and N. B. Ellison. "Social Network Sites: Definition, History and Scholarship." *Journal of Computer-Mediated Communication* 13.1 (2007): n. pag. Web.

²⁷ Hampton, Keith N., Lauren Sessions Goulet, Lee Rainie, and Kristin Purcell. "Social Networking Sites and Our Lives." *Pew Internet*. Pew Internet & American Life Project, 16 June 2011. Web. 4 Jan. 2013.

²⁸ *Ibid.*

²⁹ Lampe, Cliff, Nicole Ellison, and Charles Steinfield. "A Face(book) in the Crowd: Social Searching vs. Social Browsing." Proceedings of the 2006 20th Anniversary Conference on Computer-Supported Cooperative Work. New York, NY: ACM, 2006. 167-70. Print.

1.2 SURROGATE DECISION-MAKING

In order to understand how the information gleaned from the profiles of SNS might be of use to surrogate decision-makers, it is necessary to have a solid understanding of the ethical foundation of surrogate decision-making. A surrogate decision-maker is an individual appointed to make medical decisions for another person who is unable to make medical decisions for himself. As the word “surrogate” suggests, the appointed decision-maker is a substitute for the incompetent subject in the decision-making process. The purpose of a surrogate decision-maker is to make decisions while promoting the rights and interests of the incompetent patient for whom he makes decisions. There are four basic moral principles that inform many theories and precipitating principles in bioethics including the standards and practice of surrogate decision-making. These four principles are (1) respect for autonomy, (2) nonmaleficence, (3) beneficence and (4) justice.

1.2.1 Basic Moral Principles

1.2.1.1 Respect for Autonomy

The term “autonomy” is synonymous with “self-rule,” “self-governance” or “self-determination.” It is widely considered that two basic conditions are critical to the establishment of individual autonomy; (1) liberty and (2) agency. Liberty is defined as “independence from

controlling influence” and agency is “capacity for intentional action.”³⁰ Autonomy was originally intended to characterize the “self-rule” or “self-governance” of independent city-states. Over time, this concept has expanded in application from characterizing the source of governmental authority to individual authority.³¹ It is the *respect* for an individuals’ autonomy which has become a basic ethical value that is widely understood as an important value for its own sake.³² According to Beauchamp and Childress, “at a minimum, personal autonomy encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding.”³³ Mirroring its former application, an autonomous person dictates a self-determined trajectory and is free to make autonomous choices as an autonomous city-state might freely determine its laws.

1.2.1.2 Nonmaleficence

The principle of nonmaleficence states that there exists a duty not to do harm to another. Unlike other principles which require a positive action, nonmaleficence merely requires an abstinence from harming another and is widely regarded as synonymous with the ancient maxim “above all

³⁰ Lampe, Cliff, Nicole Ellison, and Charles Steinfield. "A Face(book) in the Crowd: Social Searching vs. Social Browsing." Proceedings of the 2006 20th Anniversary Conference on Computer-Supported Cooperative Work. New York, NY: ACM, 2006. 167-70. Print.

³¹ Beauchamp, Tom L., and James F. Childress. Principles of Biomedical Ethics. 7th ed. New York: Oxford UP, 2013. 101. Print.

³² Buchanan, Allen E., and Dan W. Brock. Deciding for Others: The Ethics of Surrogate Decision Making. Cambridge: Cambridge UP, 1990. 113-22. Print.

³³ Ibid.

[or first] do no harm.”³⁴ For example, if a child is drowning in a pool, nonmaleficence does not require any positive action on the part of the bystander in order to keep the child from drowning. Rather, nonmaleficence only requires that the bystander refrain from acting in a manner which may cause harm to the child or further diminish the child’s well-being, like pushing the child further under water.³⁵

1.2.1.3 Beneficence

Beneficence is the moral principle which describes the duty to promote the well-being of others. For example, in the aforementioned scenario where a child is drowning in a pool, beneficence requires not only that the bystander refrain from causing harm to the child, beneficence requires that the bystander act positively to further the well-being of the child in some way. This positive duty might take shape as direct intervention such as throwing the child a life preserver or pulling the child out of the water, for example. It may also include indirect intervention such as the notification of a lifeguard. In both cases, the bystander has taken *some* positive action to promote the well-being of the child.³⁶

³⁴ Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford UP, 2013. 150. Print.

³⁵ *Ibid.*

³⁶ Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford UP, 2013. 202. Print.

1.2.1.4 Justice

Most broadly, “justice is the quality of being just or right,” “refers to moral uprightness” and the “maintenance of what is just or right by the exercise of authority or power.”³⁷ Because (1) there is much disagreement about what is “right” and (2) there are many different theories of justice, for the purposes of this project the term is discussed only basically here, and peripherally below as it relates to surrogate decision-making.

1.2.2 Underlying Ethical Values in Surrogate Decision-Making

Surrogate decision-makers are necessary in certain circumstances when an individual is not competent to make his or her own medical decisions, that is, when he or she lacks, “the capacity for understanding and communication, the capacity for reasoning and deliberation” in light of a “set of values or conception of the good.”³⁸ A surrogate decision-maker may be needed to implement an instructional advance directive that is not sufficiently clear and is needed when the patient has no advance directive.³⁹

According to Buchanan and Brock, the *primary* ethical values relevant in dealing with incompetent patients are respect for individual self-determination (autonomy), concern for the individual’s well-being or “good” (which overlaps with and is supported by respect for an

³⁷ “Justice, n.” OED Online. Oxford University Press. 1 April 2014.

³⁸ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 23-25. Print.

³⁹ Meisel, Alan. “The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects.” *Kennedy Institute of Ethics Journal* 2.4 (1992): 309-45. Print.

individual's autonomy, and the principles of nonmaleficence and beneficence) and distributive justice. They also note the potential role of other values which may be relevant in dealing with incompetent patients such as community or charity, for example.⁴⁰

As previously discussed, respect for individual self-determination is of great importance to patients when they are competent, and is widely understood as an important value for its own sake. Honoring that underlying, basic value is equally important when treating incompetent patients who were previously competent. Even in the absence of an advance directive, or when one is deemed inapplicable, one of the most important parts of surrogate decision-making is honoring the incompetent person's previously expressed, presumably self-determined desires. When there is a patient who has no recorded wishes, written or otherwise, the task of surrogate decision-maker is to attempt to ascertain or discern the values of the patient, deciding on that basis what the patient would choose if he or she were a currently competent individual, able to articulate his or her self-determined values, and make the medical decision.⁴¹

Expressing concern for an individual's well-being is a complicated undertaking which first requires inquiry into what constitutes one's well-being and what concern for that well-being might entail for a given individual. In the most basic sense, concern with a patient's well-being is synonymous with being concerned with the promotion of the good of the patient. Most basically, this task requires both nonmaleficence, abstinence from doing the patient harm, and beneficence, doing positive good for the patient. In the case of a previously competent patient, concern for his

⁴⁰ Meisel, Alan. "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects." *Kennedy Institute of Ethics Journal* 2.4 (1992): 87. Print.

⁴¹ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 113-22. Print.

well-being may include concern for a number of interests. One of those interests may be his previously declared desires for his life (that which the patient believes is good for him) as we generally accept that a competent person is the best judge of what would most further his personal values and aims for his life.⁴² At times, determining what would most promote his well-being requires an understanding of the patient's values in relation to one another. For example, in certain circumstances, seemingly conflicting aims or values may require prioritization, where one or more takes precedence over others. At one time, a patient may value both the preservation of life and the avoidance of suffering, but in some cases, both values cannot be honored equally at one time. For example, a patient may choose to undergo chemotherapy in the hope of preserving his life knowing that the chemotherapeutic treatment will cause him substantial suffering. In this case, he has chosen to value the preservation of his life over the avoidance of suffering.

When considering previously competent patients, showing concern for their well-being is not wholly distinct from respecting self-determination. Well-being is often either promoted or hindered by the degree to which an individual's self-determined aims, and values governing those aims are respected and furthered. Often, respect for an individual's self-determination is a "contributor" to his well-being.⁴³ In the case of a patient who has never been competent, the determination of well-being might include an appeal to only generally accepted moral principles

⁴² Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 29. Print.

⁴³ *Ibid.*, 90.

of nonmaleficence and beneficence. For example, this would preclude the election of surgeries known to be ineffective or dangerous and include performing a curative surgery, respectively.

Distributive justice is the notion that the rights and interests of those other than the incompetent patient in question might impose limitations on the moral authority of advance directives and the standards of decision-making outlined below.⁴⁴ For example, where a patient has clearly outlined in an advance directive his wishes for extraordinary life-saving measures for end of life care that will bankrupt himself and each of his children, the duty to carry out the patient's expressed wishes is lessened because his wishes demand extraordinary financial costs on the part of his children and may present a significant burden on their future and the future of their dependents. For the purposes of this paper, the complexity of distributive justice will not be explored as the depth and nuances of its role and application in the decision-making process fall outside the scope of this project.

1.2.3 Standards for Surrogate Decision-Making

Based on the underlying ethical values and principles discussed above, surrogate decision-makers are to consider and act in accordance with one of three specific guiding standards of decision-making: the subjective standard, the substituted judgment standard, or the best interest standard. The subjective standard requires decision-making in accordance with any explicit instructions from the patient. Instructions would include written or oral instruction or proxy

⁴⁴ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 190. Print.

advance directives. This standard of decision-making most closely situates the decision-making authority in the hands of the previously competent individual and “offers the simplest extension of the competent patient’s right of self-determination to the problem of decision-making for incompetents.”⁴⁵

The substituted judgment standard is a standard of decision-making where the identified surrogate decision-maker must decide, based on his knowledge and any given information, what the patient would want or would decide if she were competent, informed about her medical care options and her present condition, including her present incompetence.⁴⁶ The substituted judgment standard, while complex in its nature, can be summarized by the following: As a surrogate decision-maker, one has a duty to make the best possible choice for the patient that most closely reflects the interests, values, and worldview of the patient in question. In this way, adherence to the substituted judgment standard expresses a commitment to the principles of respect for autonomy, nonmaleficence and beneficence.

The best interest standard of decision-making appeals to the general best interests of the patient, considering not only the preservation of life, but also suffering and the burdens of difficult treatments. The best interest standard is impersonal as opposed to the subjective and substituted judgment standards. This standard of decision-making should be most readily employed where there is no advance directive (or an inapplicable one), little or no evidence of the patient’s own wishes, or no surrogate decision-maker qualified to offer substituted

⁴⁵ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 95. Print.

⁴⁶ *Ibid.*, 94.

judgment.⁴⁷ The best interest standard seeks to determine the objective best interests of the patient, while the other two standards take account of the patient's values and preferences insofar as they can be discovered.

As previously mentioned, even if a patient who lacks decision-making capacity has executed an instructional directive, it may not give clear and unambiguous guidance in the current clinical circumstances, and a surrogate decision-maker may be required. For example, the available treatments for a given disease can change between the time that an advance directive is drafted and the time in which the patient is no longer competent and the directive is needed. Moreover, there are circumstances that may not have been anticipated in an instructional advance directive that may require a surrogate to obtain additional information or engage in further consideration.⁴⁸

The purpose of a surrogate decision-maker is to make decisions while protecting the rights and interests of incompetent patients. Accordingly, acceptable surrogate decision-makers must satisfy the following requirements: First, the decision-maker must be competent. Second, he must have sufficient knowledge and information about the patient, her condition and medical care options in order to make decisions. Third, he must be emotionally stable. Fourth, he must be

⁴⁷ Meisel, Alan. "The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Its Prospects." *Kennedy Institute of Ethics Journal* 2.4 (1992): 309-45. Print.

⁴⁸ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 104. Print.

without conflicts of interest that would compromise his ability to promote the best interests of the patient in question.⁴⁹

Most commonly it is assumed that the family or a member of the family will act as the surrogate decision-maker for an individual unless otherwise specified. (Indeed, the law in most states designates close family members as surrogates if the now incompetent patient has failed to designate one.) The family is generally considered to have the most intimate knowledge of a patient's personal values, worldview, and wishes, and is likely to be most apt to act in her best interest. For the purposes of surrogate decision-making, family is defined as, (1) a spouse or life partner, (2) adult child, (3) parent, or (4) an adult sibling.⁵⁰ However, it is not an unchangeable rule that family members are always the most appropriate surrogate decision-makers nor that they should be so recognized. In light of the goals and qualifications of surrogate decision-makers, the person who has the most intimate connection with the patient and is most likely to have the best understanding of her values and wishes would be the most appropriate choice. For example, a patient who is estranged from her family and has no domestic partner, but is close friends with her next-door neighbor, may be best served by that neighbor in the role of surrogate decision-maker. Although there are legal parameters guiding this process, there is no formula to determine an ideal surrogate decision-maker in any given case.⁵¹ At times, there are no familial

⁴⁹ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 190. Print.

⁵⁰ "Life and Death Decisions: Deciding For the Patient." *Health Law: Cases, Materials and Problems*. Ed. Barry R. Furrow, Thomas L. Greaney, Sandra H. Johnson, Timothy S. Jost, and Robert L. Schwartz. Sixth ed. St. Paul: Thomson/West, 2008. 1455.

⁵¹ *Ibid.*

connections to be found and no immediate friends who are either willing or able to take on the role of surrogate decision-maker. In such cases, there may be a surrogate appointed by a court or the case may be reviewed by an ethics committee or perhaps even by a court, particularly if there are conflicts that arise out of suggestions from the aforementioned parties concerning the patient's best interest.^{52, 53}

1.3 SELECTED LITERATURE ON THE USE OF SNS FOR SURROGATE DECISION-MAKING

Jessica Berg began her discussion of the use of SNS as informational sources for surrogate decision-making in her article, "Surrogate Decision Making in the Internet Age," published in the American Journal of Bioethics in August of 2012. Since that time, most of the additional literature has been in reaction to this article.

In her article, Berg presents a case study of a Mr. M who, at 47 has entered a comatose state with no advance directive or living will:

"Mrs. M, however, points out that he has discussed his medical situation in great detail on his Facebook page and included statements about his wishes for future care. In addition, his

⁵² Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford UP, 2013. 188-93. Print.

⁵³ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 134-151. Print.

sister has a record of his Tweets in response to the shooting of Representative Giffords in Arizona and his thoughts about whether he would want care if he were seriously disabled.⁵⁴

Berg continues to ask the following questions: “May the information on Facebook or Twitter be used to inform surrogate decisions about his care? Should they be used? What legal and ethical concerns are raised?”⁵⁵

After placing the discussion in the context of the above scenario, Berg suggests that SNS may play a valuable role in the surrogate decision-making process in multiple ways. First, Berg mentions that SNS may house “links” to information for advance directives pointing specifically to the American Academy of Hospice and Palliative Medicine (aahpm.org) and PalliativeDoctors.org.⁵⁶ Second, Berg points to the electronic storage of a legally executed document indicating health care wishes through SNS profiles. She continues by mentioning that certain states have “clearinghouses” providing for the storage of instructional directives in databases, whereas other states have more basic databases allowing only for the record of organ donation status. Berg’s article references the website, Texaslivingwill.org where citizens of Texas can find downloadable and printable forms on which they can record their health care preferences. The website encourages individuals to print and sign a copy of their completed form, but also states that the website will retain an unsigned copy of the completed form for the record. Berg concedes legal, ethical and security concerns, but indicates that electronic

⁵⁴ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 28

⁵⁵ Ibid.

⁵⁶ Ibid., 29.

documents may be more easily accessed (by the individual or surrogates) and updated by the subject if kept online. Noting that few individuals complete any sort of documents indicating preferences for medical care, Berg suggests that health care professionals may be willing to consider “less formal comments, instructions or statements made on social media” which engage issues relevant to patients’ medical care desires.⁵⁷

In an attempt to establish a link between the current framework for surrogate decision-making and the possibility of using information from SNS in the surrogate decision making process, Berg argues that the format of the information for the surrogate (paper or electronic) does not influence the relevance or value of the information. Rather, the information should be considered in light of the legitimacy, cogency, relevance and authenticity of its content. By legitimacy, it is understood that the information is not fraudulent. Information that is cogent will be coherent and understandable. Relevance of the information refers to its ability to pertain to the situation at hand, and authentic information will accurately reflect the patient’s true values. Consistency of the information, that is the degree to which the information is in accordance with what is already known about the patient, may be one other factor to be considered.

Information gleaned from SNS has the potential to provide both nonspecific *and* specific information regarding the author. Though she suggests cautions for SNS use, particularly surrounding such instances as the very non-specific use of the Facebook “like,” she suggests that there are other situations in which SNS may provide very *specific* information about the subject’s medical care wishes. Detailed comments and responses left by individuals on either their own

⁵⁷ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 29.

profile or other “pages,” can provide very specific, thorough evaluations of issues and ideas that may prove to be useful sources of information about their authors. Furthermore, that these wishes are in their original format and less subject to misunderstanding and misinterpretation compared to “spoken communication” and “the deficiencies of human memory” means that there is at least some benefit over traditional informational sources (memories, word-of-mouth) for surrogate decision making in cases where no advance directive exists.⁵⁸

Berg concludes her article by addressing some anticipated objections to her argument, citing concern for the adoption of online personas, doubts about the legal legitimacy and sufficiency of SNS information, and the accessibility or inaccessibility of SNS profile information depending on profile privacy settings. Berg notes that there is much research to be done regarding the internet and identity, but relevant research suggests that we do know that people take on different personas in everyday life; we create and sell an image of ourselves to friends, family, co-workers and authorities. Berg expects that the courts will not reject the use of SNS in cases dealing with medical decision-making because of their already accepted use in family law, employment law, and criminal law.⁵⁹ She believes however, that the biggest concern of the courts will be the possibility of fraudulent postings and fallacious information, as this is also a deep concern regarding traditional wills and oral disclosures.

Accessibility of SNS information may still be a problem in coming years and information will only be available for consideration if it is accessible. In the opening scenario, Mrs. M was in

⁵⁸ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 31.

⁵⁹ *Ibid.*, 31.

possession of the information from Mr. M's Facebook page, but it was his sister who furnished the information from his Twitter account. Clearly, the consideration of SNS information in the medical decision-making process will be dependent upon its availability. Nevertheless, with the rapid rise in use of SNS and the accessibility of some information, particularly to close family and friends, SNS information may prove helpful.

The responses to Berg's article have been varied. In Pope's article "Facebook Can Improve Surrogate Decision Making," he claims that Berg did not go far enough in her assertion that information found on SNS may be useful in the surrogate decision-making process. He argues that social media can (1) help navigate the process of the designation of a surrogate (among a group of possible candidates) and (2) identify possible surrogates for the "seemingly unbefriended," or abandoned, patients. Pope also suggests that in light of Berg's assertion that the affiliation of an advance directive or living will with an SNS profile will make individuals' wishes more accessible, more people may engage in advance health care planning.⁶⁰ In her article, "A Disability Response to Surrogate Decision Making in the Internet Age," Burke claims that patients with disabilities use technology, in particular SNS, in ways that differ from the general public. Burke anticipates the adoption of information from SNS into the surrogate decision-making process and suggests two additional types of social media, vlogs (video blogs) for the deaf and "special-interest social networks," providing a platform for condition or disability-focused communities. Burke suggests that more discussion regarding the use of SNS and social media as a whole among the disabled will be necessary in order for a surrogate, or

⁶⁰ Pope, Thaddeus Mason. "Facebook Can Improve Surrogate Decision Making." *American Journal of Bioethics* 12.10 (2012): 43.

group of decision-makers to adequately apply SNS information to the medical decision-making process for those with disabilities.⁶¹

Others have taken a more cautious approach to the employment of SNS as informational sources for surrogate decision-making. Meredith Stark and Joseph Fins consider the relationship between authentic identity and constructed online personas in their article, “The Self, Social Media and Social Construction,” as it relates to Berg’s article. While the authors are most concerned about possible abuses and misapplication of information, overall they acknowledge the possible value of information derived from SNS, with the condition that it can be verified by, or found to be congruent with, other aspects of a patient's life.⁶² Similarly, Jessica Moore and Colleen Gallagher stress caution, consideration of the context of SNS information and evaluation of the relevant content of the information.⁶³

While most responses to Berg’s article have been positive, though cautiously so, there have been a few responses representing a more skeptical view of the use of SNS as informational sources for surrogate decision-making. Tsai is skeptical of the practicality of the endeavor of obtaining, sifting through and applying information found via SNS to the medical decision-making process. She is concerned primarily with issues of online personas (the ability of individuals to portray a personality substantially different from their offline personality), lack of context for SNS posts and expresses doubt about the logistics of locating and evaluating

⁶¹ Burke, Teresa B. "A Disability Response to Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 36-37.

⁶² *Ibid.*, 38-39.

⁶³ Moore, Jessica A., and Colleen M. Gallagher. "Are We Prepared for Surrogate Decision Making in the Internet Age?" *American Journal of Bioethics* 12.10 (2012): 47-49.

information. Tsai stresses the often “permanent consequences” that result from medical decision-making and ultimately argues that, “the physical person requires and deserves more consideration than his or her public persona.”⁶⁴ That is, though potentially accessible indefinitely and perhaps seemingly robust in substance, she argues that online personas (assuming authenticity) comprise only a small portion of the depth of one’s personhood and identity. As a result, she doubts the substantive helpfulness of even the most seemingly authentic SNS profiles and discourages the use of information from SNS sites in the surrogate decision-making process.

Feltz and Abt are extremely skeptical of Berg’s arguments. In their response to her original article they suggest that (1) the mere existence of additional information may confuse surrogates or lead them to doubt otherwise more confident decisions and (2) without the existence of empirical evidence demonstrating the value of SNS information for surrogate decision-making (value in the form of more “accurate” decision-making), such information should not be used. In addition, they suggest, through a series of empirical experimentation that SNS information may have a questionable usefulness for surrogates.⁶⁵ For the purpose of the article, the authors polled 211 participants in an online panel (~61% male, ~39% female, ages 18-70 years) given a hypothetical surrogate decision-making scenario in which the participant was the surrogate decision-maker with the option to use information from an SNS in their decision-making process. In one of the experiments:

⁶⁴ Trevanian Tsai, Nancey. "Consideration in Surrogate Decision Making in the Internet Age." *The American Journal of Bioethics* 12.10 (2012): 51.

⁶⁵ Feltz, Adam, and Taylor Abt. "Claims About Surrogate Decision-Making Accuracy Require Empirical Evidence." *The American Journal of Bioethics* 12.10 (2012): 41-43.

“All participants answered a pair of questions: (1) Would your mother wish to be placed on a feeding tube? (Yes/No), and (2) How confident are you in your decision? After answering these questions, participants were randomly assigned to read contrary information from only one of a hypothetical (i) Twitter account, (ii) Facebook account, or (iii) blog. For example, if participants answered that their mother would want a feeding tube, some were directed to a hypothetical Twitter account where their mother tweeted “very interesting & touching article” about an article titled “Why I Chose Against a Feeding Tube.””⁶⁶

Feltz and Abt found that among those who were surveyed, information from SNS *could* influence the opinions of the hypothetical surrogates, but that when the surrogates were asked if they believed that information from SNS could be valuable in the decision-making process, only 34% said that they would use information found on SNS to make such decisions. Ultimately, Feltz and Abt argued that without empirical evidence establishing the efficacy of the practice in terms of its ability to generate more “accurate” decisions for incompetents, or its helpfulness to surrogates, the use of SNS as informational sources for surrogate decision-making could not be advised.⁶⁷

Berg agrees that more research must be done in order to more fully understand the place and parameters of applicability for information from SNS in surrogate decision-making. Moreover, she affirms that empirical evidence to support the usefulness of information gleaned from SNS in surrogate decision-making would be helpful. However, Berg is careful to point out

⁶⁶ Feltz, Adam, and Taylor Abt. "Claims About Surrogate Decision-Making Accuracy Require Empirical Evidence." *The American Journal of Bioethics* 12.10 (2012): 42.

⁶⁷ *Ibid.*, 41-43.

that we have yet to require any empirical evidence to evaluate the usefulness of other informational sources (memories, conversations prior to the incapacity of the patient) for surrogate decision-making. It might be added here that it would be an extremely difficult undertaking to try to evaluate (for empirical purposes) many of the commonly used and accepted informational sources mentioned above, particularly with end-of-life care, where patients may never regain the capacity to reflect on decisions which were made for them in their incompetence. Berg also points out that even written advance directives may themselves be vague or less directly applicable given a specific situation in which a patient may be found. Nonetheless, it is unlikely that one would “say they [advance directives] should be ignored because of the difficulties their examination would pose to the surrogates.”⁶⁸ Berg argues that in sifting through information from multiple sources, including those which are already well accepted forms of information concerning wishes regarding medical care, surrogates likely go through quite a bit of information which may not be directly relevant to the issue at hand and that a desire to exclude information from SNS altogether based on the possible difficulty of the examination of the source is not an appropriate reason for total exclusion. Berg clarifies that while she is advocating for the possibility for use of *specific, relevant* information from SNS, one must be careful about any information used to determine people’s wishes.⁶⁹ She first argues that surrogates routinely sort through relevant *and* irrelevant information, whether from social media or other more traditional sources. Because of this, the usefulness of any source should

⁶⁸ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

⁶⁹ *Ibid.*

always be determined first. Second, Berg argues that the “confidence” in one’s decision that Feltz and Abt appeal to is not an appropriate measure of usefulness, saying “the goal is not to ensure confident surrogates,” but to provide accurate information to help make decisions “most in accord with the patient’s wishes.”⁷⁰ Confidence, she suggests, can in fact be harmful if the information used to arrive at that state is inaccurate. Finally, Berg completes her response to Feltz and Abt by examining the flaws in their empirical study. She points out that the experimental methodology itself gives preference to the inaccuracy of social media by introducing knowingly false information, and only then asking the study participants their opinions regarding social media’s accuracy in reflecting on the hypothetical scenario. Berg argues:

“The fact that some information could influence surrogate decisions is not the question. I can only imagine how unhelpful it would be to read an imaginary social network site (SNS) belonging to one’s mother containing information that directly contradicts a choice you just made. Why would this be an indication of the usefulness of real statements? And, given the setup, the confidence judgment of surrogates most certainly should be reduced (they just read something that contradicted their initial belief about preferences). This would be true of any information provided that contradicted initial beliefs.”

“Moreover, the “no” response to the question about accuracy of social media information also makes sense given a design that deliberately provided contradictory information—in other words, information that does not line up with what the surrogate believed the person wanted. So what does all of this show? If you give people made-up contradictory information about someone they know well, they may be less likely to believe the accuracy of the (false!) information. This tells us very little about how social media may

⁷⁰ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

be used in real-life situations, such as one analogous to the Mr. M case described in my article.”⁷¹

⁷¹ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W2.

2.0 THE USES OF SNS IN SURROGATE DECISION-MAKING

2.1.1 Identifying Surrogate Decision-Makers

Because of the personal nature of the information on social network profiles, the public way in which it is displayed, and the interactive, participatory engagement that forms the basis of these sites, such profiles may be useful in surrogate decision-making in a number of ways. First, as Pope suggested in his article, "Facebook Can Improve Surrogate Decision Making," they may aid in identifying individuals who have personal knowledge of the patient who may serve as a surrogate decision-maker.⁷² In making this assertion, Pope is appealing to the value of the multi-media content of the SNS profile (pictures, videos, text posts, etc.) and the "friend" lists, which may provide relevant contacts to a court or health care team.

Facebook, the most widely used SNS at this time has been in the process of introducing facial recognition technology to its user interface experience.⁷³ While this program is currently enabled only in the United States with questionable accuracy in correctly determining an

⁷² Pope, Thaddeus Mason. "Facebook Can Improve Surrogate Decision Making." *American Journal of Bioethics* 12.10 (2012): 43-45.

⁷³ Duggan, Maeve, and Joanna Brenner. "The Demographics of Social Media Users- 2012." *Pew Internet & American Life Project*. Pew Research Center, 14 Feb. 2013. Web. 20 Feb. 2013

individual's identity in photographs, much can be said about the possible benefit from this functionality. One could use this technology to (1) ascertain the identity of an unknown, incompetent patient in order to locate an appropriate surrogate, or (2) identify another in a photograph or post on the patient's SNS profile who may be able to either act as a surrogate, or provide information about the patient so that another, more appropriate individual could be sought.⁷⁴ Consider a scenario in which a patient has remained on life support in the ICU for many months without any identification. Physicians and members of his care team might provide reasonable and appropriate basic care for the patient, but would have no ability to provide treatment sensitive to his desires and values surrounding life and death. If members of his health care team were able to use Facebook or another SNS with facial recognition technology to look for him, there may be a possibility of locating an SNS profile created by the patient, unearthing his identity, which may itself be instrumental in helping to locate family or another surrogate candidate through missing persons listings or other avenues. Additionally, they may be able to identify someone else through the SNS (pictures with the patient, posts or via other interactive media on SNS) who knows the patient well and could act as a surrogate. This person may also be helpful in identifying a more appropriate surrogate, based on her knowledge of the patient.

⁷⁴ Hsu, Jeremy. "Face of the Future: How Facial-Recognition Tech Will Change Everything." *TechNewsDaily.com*. N.p., 10 June 2013. Web. 10 June 2013.

2.1.2 Informational Sources for Surrogate Decision-Makers

SNS profiles may provide insight into the interests, values, and worldview of the individual who created the profile that might be useful in fleshing out systems of values for use in surrogate decision-making. Moreover, various media may be employed in the constitution of social network profiles that both add credibility to information recorded and inform an understanding of the patient on a deeper level. For example, consider a scenario where parents are the appointed surrogates for their 25 year old daughter who is in a persistent vegetative state. They are aware that their daughter has been a devout Muslim for the last 5 years, despite being raised as a cultural Christian. The parents are willing to act as their daughter's decision-makers, but they are concerned about their lack of connection to her religious life and the degree to which that disconnect may affect their ability to provide substituted judgment. In an attempt to understand the relevance which that aspect of her life might have in the context of their decision-making process, they reach out to her MySpace account where she is the moderator of numerous discussion groups on religious topics, including one on the Islamic approach to the definition of death. Her parents choose to review her writing and her comments in response to others' posts on the topic. Furthermore, her parents are able to identify and reach out to several members of their daughter's religious community who are also affiliated with the posts on the discussion groups. They hope that close friends may be able to provide personal insight into her views on death, the degree to which she may have held strictly to traditional religious doctrines and possible treatment options in light of her established religious convictions.

Social networking profiles may be particularly useful in cases where surrogate decision makers are not well informed about the individual for whom they are charged with making

decisions. Consider the aforementioned case where the named surrogate is the patient's next door neighbor. Perhaps this person is the best possible choice for a decision-maker and is willing, but she is somewhat hesitant about assuming the role without some direction. Perhaps she might look to estranged family members, review some of the patient's various correspondences, look to organizations of which the patient was a part, or consult sacred texts that were of value to the patient. However, she may have some difficulty even knowing various aspects of the now incompetent patient's values, simply because she was not an active part of a certain dimension of the patient's life, or even aware of these various resources regarding the patient's values. Social networking profiles could prove to be vastly informative in cases such as this. While she might find only that her neighbor enjoys various kinds of ethnic foods, she may also discover a profile "link" to a blog, revealing that her neighbor was a prolific writer who kept an extensive record of her experience caring at home for her dying father. The blog includes lengthy posts on her father's suffering, quality of life, desire to live and her reaction to and reflection upon the experience of his dying. Such a substantive, reflective account would certainly be informative about the patient herself and may be a valuable source of relevant and specific information, which would facilitate application of the substituted judgment standard. Granted, as Berg mentions, social network profiles will not always be extremely informative, as much would depend on the kind of information revealed by the patient, but they can bring relevant new ideas and points of interest to the decision-making process that were previously unknown to the surrogate decision-maker.

In an attempt to facilitate application of the subjective standard, the information from SNS profiles could also prove valuable in cases where the patient's advance directive is not relevant to the patient's current clinical situation. As discussed above, there are two main reasons

for supplementing or departing from an otherwise legitimate advance directive. First, if the treatment options and prognosis for a given disease have changed greatly since the drafting of the advance directive, it may be determined that other, more appropriate courses of action are now available that were not available while the patient was competent. For example, a young man affected by muscular dystrophy wrote an advance directive at eighteen years of age regarding his wishes for medical treatment and end-of-life care. The advance directive was written with the expectation that as his muscles deteriorated according to the natural disease process, he is likely to experience respiratory insufficiency and eventually arrest and need intubation, or suffer from a secondary condition as a result of the disease that would render him unconscious or otherwise unable to express his wishes. In preparation for that time, he indicated the desire to be made comfortable, but that nothing extraordinary be done in order to extend his life. Given that there was no cure or treatment to significantly delay the natural process of the disease at the time of writing the advance directive, he made his desires clear based on the information available regarding his condition. He was in his mid-twenties when he became incapacitated to the degree that he was unable to express his wishes any longer. Shortly thereafter, it was found out that a new treatment was available for his condition which would halt the progress of the disease and restore his ability to breathe on his own though there was no evidence to suggest any additional functionality would be restored. Because he was confined to a wheelchair for much of his life, he became heavily involved in online blogging communities focusing on his disease. In several entries, he posted statements about desiring to live longer, to be around for his nieces and nephews and have a girlfriend one day. The availability of new medical treatment, which would preserve and restore some goods of life, calls into question the relevance of his previous statements in his advance directive which did not take this new

treatment option into consideration. In such cases, more substantive up-to-date information provided by the patient through constant, even casual interactions through SNS, may shed light on desires which can be honored given new circumstances after the advance directive has already been created.

Second, advance directives might provide inadequate guidance regarding the situation at hand. In these cases, other sources of information may be consulted as evidence of patient's values given a specific set of circumstances. These scenarios may involve decision-making in accordance with the subjective standard, insofar as it can be applied and supplemented by the substituted judgment standard. No one advance directive can be assumed to be capable of accounting for the broad scope of all medical decisions, end of life issues, or treatment options even though, at times, the spirit reflected in the instructional advance directive can be understood and applied to issues not directly contemplated in the document. Similarly, like other informational sources that display the spirit of the patient's life, her values and priorities, social network profiles can more deeply inform decision-makers by providing a general sense of the patient's wishes and values.⁷⁵

2.1.3 Information Sources for Resolving Conflicts Among Surrogate Decision-Makers

Information from social network profiles can also be used as evidence of values in cases where there are disagreements between potential surrogate decision-makers or when an individual who

⁷⁵ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 98-112. Print.

is not the named surrogate brings the profile as evidence of values and interests contrary to those on which the surrogate is deciding. Consider a situation where adult children are making healthcare decisions for an aging parent but only the eldest son is legally named as a surrogate. The eldest son is sure that his mother would not want to continue life on a ventilator if she were not expected to be able to return to live alone at home, even if she were able to be successfully weaned from a ventilator over several months. He cites a conversation he had with his mother years before, where she said she could never sell her house or consider living elsewhere after living there for over 50 years. The two younger sons vehemently disagree with the elder's assertion that their mother would rather be removed from a ventilator at this time and allowed to die, even if her weaning were uncertain and she were forced to relocate to an assisted living facility. The two younger sons insist that their mother would prefer life, *even* in a diminished capacity and away from her home of 50 years. As evidence of this assertion, one of the younger sons produces their mother's Facebook post in reaction to an article in the *Atlantic*, "Make Your Wishes Known." The article discusses how a young man's family removes him from life support based on the assumption that as a bricklayer, he would not want to live life if he had to undergo a 4 limb amputation, even if there was a possibility that he would live for 35-40 more years. The article explained that upon the removal of life support, the patient began to breathe on his own and when he was able to understand the details of his condition and the necessity of the amputations, he replied, "Do whatever it takes."⁷⁶ In her reaction post, the patient insisted that human life is valuable in all of its states and must be preserved in all cases where there is even a

⁷⁶ Masoodi, Ashwaq. "Make Your Wishes Known." *The Atlantic*. Atlantic Media Company, 10 July 2013. Web. 10 July 2013.

slight possibility that someone, like the patient described, could regain consciousness and enjoy a reasonable quality of life. Her younger sons insist that her post in reaction to the article indicates a preference for life, even if there is a small possibility for regaining consciousness and the enjoyment of life—even a life spent in a diminished capacity and a different home space. The younger sons feel that the elder’s conversation is out of context because the time of that conversation was in close proximity to the death of their father. They believe that in grief, she was emotionally clinging to the familiar and they present her Facebook post as evidence of a more soberly articulated statement of value.

When conflicts in medical decision-making arise, it is the job of the surrogates, health care professionals, ethics committees, and sometimes courts or other individuals, to resolve the conflict on behalf of the incompetent patient. Especially in the case of conflicts, the profile information might be highly valuable if it is the means through which new, relevant information is brought to light. It may also be especially valuable if it is a source of information that drastically changes the proposed decision-making plan (prior to the revelation of the information from SNS) in favor of previously unbeknownst wishes of the patient. It might be used as one source of evidence for honoring one value over another in the case of competing values, (e.g. the preservation of life vs. avoiding suffering) in surrogate decision-making. It might be used to better inform ethics committees about the personal values of the incompetent patient in question; or it may even be used as evidence in a court of law, depending on the nature and degree of disagreement and information provided by the SNS.

A great strength of the argument for the use of SNS in surrogate decision-making is that it can function in much the same way as other, more traditional sources. Nevertheless, there is some ambiguity in how to employ the information from SNS when it is being considered

alongside contrary evidence. In cases of conflicting information, the information from SNS must be assessed for legitimacy, relevance (which may include consideration of the specificity of the information) evaluated for cogency and authenticity, as suggested earlier and supported by Berg.^{77,78} Both sources of information should be evaluated as such and compared according to the degree to which they satisfy those criteria. For example, in the case discussed above, one might evaluate the conflicting information in light of 3 main points:

1. The information from SNS was relevant *and* specific. The information was relevant in informing on the patient's general views about the value of life. It also gave specific direction concerning her values and ideas on a scenario that was similar to her own.
2. The information the eldest son revealed, while perhaps relevant, is not specific and therefore less helpful in reference to the particular situation—especially when there is information available that is both relevant *and* more specific—therefore increasing the degree of its relevance.
3. Not only does the information from SNS seem helpful, (positive) but the scenario also raises some (negative) doubts over the memories of her eldest son. (1) The conversation he is referencing took place years prior. Though his memory may be a correct representation of his mother's views at the time, the post from Facebook suggests that something has changed in the way his mother thinks about issues of life and death. Note

⁷⁷ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

⁷⁸ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 31.

that this is a concern not only with memories, but addressed with SNS and other sources as well. There may be changes over time and where there is evidence of such a change, the prior remarks or memories may be considered less weighty than the more recent information. (2) There is concern that the conversation has been taken out of context. With information from SNS or any other information that may be used to reconstruct values, context is one of the key considerations for determining the weightiness of the information. The two younger sons remark that the conversation took place years ago, *and* shortly after the death of their father. Death of a spouse is known to be a major source of stress, cause for depression or other personal issues that have shown to render someone “not quite themselves” for a period of time following crisis or grief process. While I would not completely discount the conversation on which the older son is basing his opinion, there is reason to consider this comment with caution—and with less weight, based on both the timing and context in which it was had.

Though I have explained how the evaluation of the conflicting information might take place in the specific case above, what if the informational sources were equally relevant, specific and contextual? In the case above, a plan for assessing the value of information was more straightforward because one of the conflicting sources was diminished in relevance through consideration of its specificity and context. In such cases, the decision-making process would have to be dealt with in a way that one might deal with a conflict over a medical decision where non-electronic informational sources are equally relevant, specific and cogent. Surrogate decision-making is often a difficult undertaking when there is confusion about what a patient might want. In a case where all informational sources are equal, the problem becomes one about difficult decision-making generally and is not unique to information from SNS.

2.2 THE CURRENT TREATMENT OF INFORMATION FROM SOCIAL NETWORK SITES IN LAW AND POLICY

At present, information found on social network sites is being used as evidence of intention and criminal activity by police and court systems and has been used as an investigative tool by police authorities in the United States. This is particularly relevant to the discussion of the use of information from SNS in the surrogate decision-making process because (1) it is a testament to the perceived truth and legitimacy of information found on SNS and (2) it is setting precedent for the legitimacy of such information in legal discourse. According to an article published on the FBI website regarding its evolving social media policy, “social media can provide an invaluable source of information for investigators. Criminals will use social media to share information about their whereabouts and those of their associates. They also have been known to share photos and videos of their criminal acts. Such electronic information can help apprehend fugitives, single out associate suspects, link individuals to street gangs, and provide evidence of criminal activity.”⁷⁹ In 2006, police attempted to arrest two University of Illinois students for public urination; however, one of the students fled the scene prior to arrest. After the apprehended student claimed he did not know the other individual, police were able to ascertain the identity of the other student on Facebook through connections made with other individuals through the apprehended student’s account. This information resulted in a fine for the original

⁷⁹ Stuart, Robert D. "Social Media: Establishing Criteria for Law Enforcement Use." *The FBI*. Federal Bureau of Investigation, 22 Jan. 2013. Web. 18 Feb. 2013.

offense along with a fine for “obstruction of justice,” which was brought to light as an added offense through information from Facebook.⁸⁰

In January of 2007, 19-year-old Anthony Alvino was involved in a hit-and-run accident where he hit University of Connecticut student, Carlee Wines with his SUV, and she died of resulting injuries. Police were able to track down Alvino through his Facebook account and link him to the crime. The evidence captured from Facebook, along with indirect connections made as a result of the Facebook information, led to his conviction in 2008.^{81, 82} Of particular interest to the discussion of SNS as a source of information on the identity of individuals using facial recognition features is an ongoing effort to identify the body of a deceased woman, led by the Kentucky State Police. On January 11, 2011, the Kentucky State Police decided to publish photographs of jewelry found on the body, a photograph of her tattoo and a picture of a “forensic facial reconstruction” for identification.⁸³ Though they have yet to identify the woman, they were able to discover some information about her jewelry which they hope might be helpful in identifying the woman in the future.⁸⁴

In 2009, a Canadian woman, Nathalie Blanchard, had her health insurance terminated as a result of photographs that her insurance agent found in her Facebook profile. At the time the

⁸⁰ Martinez, Kiyoshi. "Student Arrested after Police Facebook Him." *The Daily Illini*. N.p., 1 Aug. 2006. Web. 16 Dec. 2013.

⁸¹ L.I. Man Sentenced to Prison for Campus Hit and Run." *The New York Times*. The Associated Press, 24 Jan. 2008. Web. 16 Dec. 2013.

⁸² Porter, Andrew. "Alvino Sentenced To 37 Months." *The UConn Daily Campus*. N.p., 24 Jan. 2008. Web. 16 Dec. 2013.

⁸³ Highland, Deborah. "KSP Turns to Facebook as Investigative Tool." *Bowling Green Daily News*. N.p., 3 Apr. 2011. Web. 16 Dec. 2013.

⁸⁴ Ibid.

photographs were taken and posted to her profile, she was on medical leave from her job due to a diagnosis of depression. In the photographs, Blanchard was depicted at a bar with friends, seemingly having fun and unaffected by her depression. Blanchard fought the termination on the basis that those photographs provided little information into the totality of her condition or well-being at the time and that termination based on such limited information was short-sighted. The insurance company maintained that while it "would not deny or terminate a valid claim solely based on information published on Web sites such as Facebook," it may be used as a legitimate source of information that fit into a larger narrative.⁸⁵

2.3 TOWARD THE USE OF SNS IN THE SURROGATE DECISION-MAKING PROCESS

Despite the recent interest displayed through hypothetical case studies in current academic literature regarding the use of SNS as informational sources for surrogate decision-making, up to this point there has not been any publicly reported use of SNS in this way. Some of the reasons for the lack of documented use may be discomfort due to unfamiliarity with the electronic platform from which the information would be taken, or because there is some doubt in the helpfulness or legitimacy of the content of the information, both of which have been mentioned above. Moreover, surrogate decision-making is rarely publicly reported, unlike the legal cases

⁸⁵ Heussner, Ki Mae. "Woman Loses Benefits After Posting Facebook Pics." *ABC News*. ABC News Network, 23 Nov. 2009. Web. 01 Aug. 2013.

discussed above, which may account for the current and potentially future lack of coverage in literature. Because the concept of using SNS as informational sources for surrogate decision-makers is, at this time, somewhat novel, the aforementioned issues may well play a part in the failure to translate this idea from theory into practice. Nonetheless, hindrances that exist may lessen over time as the use of information from SNS is normalized in law enforcement and in legal discourse and as more organizations enact social media policies.

Perhaps the biggest obstacle to using information from SNS in the surrogate decision-making process will be in the difficulty of determining informational relevance. In both of her articles discussing the use of SNS as informational sources for surrogate decision-makers, Berg defends the use of information from SNS by arguing that, "Surrogates are likely to have to sort through irrelevant information, whether gleaned from social media or elsewhere," indicating that sifting through information on SNS is not appreciably different from dealing with any other informational source that a surrogate might consult.⁸⁶ While this may be the case for many surrogates, particularly for those who are not intimately acquainted with those for whom they are making decisions, developing criteria to assess the relevance of information is critical to the successful and efficient implementation of using SNS as an informational source for surrogate decision-making. A categorization scheme will aid in ensuring that a definitive decision be made regarding the relevance of the information discovered. According to Berg, determining

⁸⁶ Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

informational relevance is one of the core conditions that governs the use of SNS as an informational source.⁸⁷

I agree with Berg and propose the following fourfold classification scheme for assessing the relevance of information from SNS: “clearly relevant,” “possibly relevant,” “possibly irrelevant” and “clearly irrelevant.” I suggest this specific scheme for three reasons: (1) The fourfold structure of classification is general and therefore should include most, if not all cases. However the classification scheme is sufficiently specific to provide meaningful guidance in assessing the relevance of SNS information. (2) This classification scheme deals directly and efficiently with the extremes, “clearly relevant” and “clearly irrelevant.” In cases of “clearly relevant” information, a surrogate, with clinical support, can begin to consider the level and manner of employment for the SNS information. In cases of “clearly irrelevant” information, the surrogate may immediately remove from the decision-making process the consideration of extraneous information. (3) In scenarios where the information obtained is “possibly relevant” or “possibly irrelevant” the classification scheme encourages caution and additional measures to assess the relevance of the information are required. It is worth noting that this suggested scheme is not exclusive to information obtained from SNS and may also be useful for evaluating information obtained through traditional and other non-traditional sources.

The evaluation of relevance of information into one of the aforementioned categories may be difficult to determine, but may be facilitated by the following questions:

⁸⁷ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 31.

1. Does the information relate to the issue at hand generally (e.g. evidence of some general values or life goals of the patient)?
2. Does the information relate to the issue at hand specifically?

If the information does not in any way relate to the situation at hand, even generally, the information would be considered “clearly irrelevant” and dismissed. If the information relates to the situation generally (speaking perhaps to larger life goals or values of the patient) it is potentially relevant for use in the decision-making process and may be “clearly relevant,” “possibly relevant” or “possibly irrelevant” for purposes of medical decision-making. If the information is relevant, then it can be helpful to surrogates and the question becomes one of the degree of the information’s usefulness. The usefulness of the information will depend in part on how specific it is in relation to the medical decision: Does it only provide general information about the patient’s values or does it provide specific information about the patient’s wishes in the current medical situation? If the former, the information is relevant, but not helpful to the surrogate. If the latter, it is relevant and very helpful to the surrogate. Once relevance is determined, the information can be treated as any other informational source: evaluated for content, context and weighed alongside information from other sources.

I see the process of evaluating the content and context of the information to be the most difficult—particularly when it does not clearly fall into the categories of “clearly relevant” or “clearly irrelevant.” An example of a straightforward scenario is the aforementioned case where a next-door neighbor was serving as the surrogate decision-maker for a patient and there was a discovery of a blog that detailed the experience of the patient caring for her dying father. In the blog, there was information concerning her experiences and reactions to his medical care and eventual death. This case would represent a clear instance in which information would prove

very relevant to a surrogate trying to piece together what the patient would want, if she were able to decide for herself.

Consider another case where an adult child is looking through his father's Facebook profile for information concerning his father's life since the son and his family have lived abroad for many years and have had little contact with the father. The son is unsure of his father's desire for invasive medical treatment when there is only a small benefit to be had. On his father's profile there is little information about the man himself. It becomes clear that he created the profile primarily to view pictures, videos and information about his young grandchildren abroad. This profile would be of little relevance to the decision-making process and would be easily categorized as "clearly irrelevant" for the purposes of informing in medical decision-making.

Some of the possibly relevant cases may include a scenario where a patient has remarked on several news articles regarding the death of actress Natasha Richardson in 2009, as a result of a head injury while skiing. She was eventually removed from life support as requested by her husband.⁸⁸ The patient had posted several responses about her enjoyment of the late actresses work and how in a "similar situation," she would also "want all the tubes to be removed" so she could "die in peace." There are several difficulties in the translation of the above situation with the late actress to the immediate situation of the incompetent patient. It would be hard to know what a "similar situation" might entail. It was determined that Natasha Richardson was brain dead, but the patient, in her current state is in a persistent vegetative state. Would the patient have considered that a "similar" enough condition to desire the removal of life sustaining care?

⁸⁸ Marikar, Sheila. "Natasha Richardson Died of Epidural Hematoma After Skiing Accident." *ABC News*. ABC News Network, 19 Mar. 2009. Web. 11 Nov. 2013.

Would it perhaps be similar enough when the duration of the persistent vegetative state extended long enough for it to be reclassified as a permanent vegetative state? While it is certainly difficult to parse and compare the details of the medical condition that would have inclined the patient to write the responses she did, it is also difficult, and a delicate undertaking to try to judge the spirit of the voiced emotion. Perhaps a safer interpretation might note her general desire to live, but when there is no capacity for consciousness, relationships, enjoyment of and interaction with the world, she would value the ability to “rest” in death over that of life.

Moreover, this information might be found to be consistent with a conversation her friend remembers that she once had with her mother several years prior, as her mother considered her own wishes for medical care and upcoming end-of-life decision-making. In a circumstance like this, the patient’s Facebook posts are relevant, though not specific enough to the exact condition in which the patient is currently and therefore unable to be decisive without additional evidence. Nonetheless her Facebook posts do speak to preferences about existence in the world and a greater attitude about life and death. Cases like this might be considered in light of other evidence of values like the remembered conversation, along with the information drawn from the SNS.

Consider also a case that involves a critically ill man in his upper-60’s who identifies as a Catholic but has a history of severe mental health issues and suicidal tendencies which have not rendered him legally incompetent at any time. The man is highly non-compliant with medication and treatment plans, and it is thought by his mental health providers that his non-compliance is a result of his mental illness and desire to die by “passive” suicide because he believes active suicide to be a damning sin according to his faith. The man is currently in a coma due to a recent accidental head trauma, and it is unclear if he will ever recover. At various points in his life, the

man has indicated conflicting desires regarding lifesaving, aggressive medical treatment and end-of-life wishes. According to information provided by his mental health care providers at one local hospital, he has a three-and-one-half year old DNR/DNI order on file, and at another he has requested a Full Code status which is on file, neither of which were filed at the hospital where the patient currently resides. The request for the Full Code status is slightly more recent than the DNR/DNI request, by six months. The man has no family and there is a surrogate decision-maker appointed by a court to make his medical decisions. The surrogate has had information provided to her from his mental health care providers that indicate that he would not want extraordinary medical care at this time and has “made peace” with the idea of death in his late 60’s. The surrogate has also been made aware of an SNS profile kept by the man where he would occasionally journal for therapeutic purposes. Within the week previous to his accident, the surrogate notices an entry where the patient grieves what he calls “a wasted life” and vows to turn his life around, reconnect with his estranged parish community and voices a desire to take control of the life he has left to live. He records a prayer asking for forgiveness for his past infractions and begs for additional time in life to “make up for what has been squandered.” The surrogate has a difficult decision to make: whether to have the patient undergo aggressive, significantly burdensome treatments which may afford him little improvement, or to discontinue treatment altogether and allow him to die. In order to make this decision, the surrogate must do two things: (1) She must determine the relevance of the information from SNS and (2) she must determine the weight of the information and its value in determining a course of action. The information is not specific, which precludes its ability to be “clearly relevant.” The information is “possibly relevant” or “possibly irrelevant” to the degree that it speaks to the patient’s more general values as it relates to the desire to live, despite being directly in conflict with other

previously voiced desires. In determining the weightiness of the information and its value in the decision-making process, the surrogate will have to employ other informational sources as well as an evaluation of the content and context of all information to which she has access.

A longitudinal view of his stance on issues of taxing medical treatments and end-of-life care seem to indicate a desire to discontinue treatment and life support. This is further confirmed by several of his mental health care providers. Nevertheless, this apparent sudden shift in his values and goals for his life discovered in his electronic journal entry indicate that more consideration ought to be given to his current wishes. It is unclear if this recent change was a result of solemn, deliberate decision-making or a brief, one-time change in mood. The surrogate would have to weigh the burdensome treatment option and past declarations about life against his ongoing mental health issues which could have affected mood changes and the possibility of a genuine desire to live and live differently. In this case, the voiced desire to take a new hold on his life, as well as the several year old request for a Full Code status are outliers to the majority of what he has previously indicated and may be less weighty in light of the context of his treatment and medical history. However, a strong articulation of the desire to live, particularly in contrast to previous statements, makes a compelling case for treatment.

The inclusion of, or general acceptance of the use of SNS as informational sources for surrogate decision-makers will not likely make a huge “wave” in the manner in which difficult, often weighty decisions are made for incompetent patients. Nonetheless, I believe helpful arguments for the inclusion, or the possibility of its inclusion in the decision-making process have been made. The purpose of arguing for its inclusion in the decision-making process, for all the aforementioned reasons, is in an effort to make decisions for patients who cannot make those decisions for themselves in accordance with their authentic values. Regardless of the

informational sources used to make those decisions, coming to conclusions regarding major medical procedures or potential end-of-life choices should come out of sober and deliberate consideration. The proposed use of SNS as informational sources for those decisions should not change that. The use of information from SNS in the attempt to make decisions for patients in accordance with the subjective standard or substituted judgment standard is as complicated as it may be helpful, much like many other informational sources. I am inclined to agree with Berg when she says that, “substituted judgment is in many ways a flawed concept and rarely easy to determine.” The goal of using SNS as informational sources is not meant to simplify the process of making momentous decisions. Its use is suggested with the hope that in some cases it may further the efforts to make medical decisions for patients which are consistent with what they would have decided for themselves.

3.0 CONCERNS SURROUNDING THE USE OF SNS AS INFORMATIONAL RESOURCES FOR SURROGATE DECISION-MAKING

The concerns regarding the use of SNS as informational resources for surrogate decision-making which will be addressed in this section fall roughly into two categories: (1) Possible hazards and cautions to consider when employing SNS in the medical decision-making process and (2) the clinical and practical dilemmas that arise when SNS information is sought for decision-making purposes.

3.1 POTENTIAL HAZARDS AND CAUTIONS

Berg rightly identified some cautions in her original article regarding the use of SNS as informational sources for surrogate decision-making. Indeed, as Berg and other authors suggest, the reliability and consistency of the information found must be considered in order to prevent grievous errors in the construction of an individual's values.⁸⁹ One must be wary of seemingly out of character remarks, and attempt to contextualize statements into the broader understanding

⁸⁹ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 30-31.

of the subject's personhood.⁹⁰ As it is for examining other informational sources and making decisions, it is crucial to know when looking for information on SNS if a patient struggled with depression, other mental health issues, or had an alcohol or substance abuse problem. These issues may significantly color the content of the information posted on an SNS profile and mark a significant feature regarding their personhood. Furthermore, the evaluation and consideration of the emotional and mental state of the patient at the time of the writing or "post" must also factor into the weight given the assertion. For example, in his article, "When You Fall Out of Love, This Is What Facebook Sees," James Hamblin points out that the average Facebook profile sees a "225% increase [in] the average volume of interactions" in the days immediately following a break-up.⁹¹ Whether this statistic carries over to other stressful life events or crisis scenarios is currently unknown; however, data like this may be relevant for determining or appropriately considering a patient's mental and emotional state at the time they chose to publish information.

On the one hand, a patient who had written at length about her wishes following the death of a loved one with thoughtful, intentional and relevant insight, may have provided valuable information through SNS for use in creating a fuller picture of general values governing her life and specific desires regarding treatment. However, the opposite may be true in instances where an individual adds a significant amount of content to the SNS profile, but appears to be lashing out in grief or heartbreak. In cases where a patient is lashing out, he may indicate preferences he

⁹⁰Moore, Jessica A., and Colleen M. Gallagher. "Are We Prepared for Surrogate Decision Making in the Internet Age?" *American Journal of Bioethics* 12.10 (2012): 47-49.

⁹¹ Hamblin, James. "When You Fall Out of Love, This Is What Facebook Sees." *The Atlantic*. Atlantic Media Company, 18 Feb. 2014. Web. 18 Feb. 2014.

might otherwise find unacceptable under different circumstances. To complicate things further, the authenticity and sobriety with which individuals post information to an SNS profile after or amidst crisis situations (which is already difficult to discern from SNS directly) is likely to vary from patient to patient. Berg and other authors are wise to stress the importance of consistency when analyzing the information from SNS, particularly when other informational sources are also available. It is important to reemphasize that judging the consistency of information gleaned from SNS is not a measure of caution only to be applied to information from SNS. It is also a caution that ought to be applied to memories, or recollections of prior conversations concerning wishes for medical care or end-of-life decision-making in more traditional surrogate decision making processes.⁹²

Berg and other authors have been careful to point out that the electronic nature of an informational source should not be a basis on which to discredit it.⁹³ While that position seems well-reasoned, it would be wise to consider unforeseen implications for using information gleaned from SNS and analyze that information in terms of the unique challenges that may arise with its use. The electronic format of this information may factor into how it is uncovered or received. Because SNS can be created with flexibility and be changed from very public to very private at any moment, it is unlikely that an assumption can be made regarding the *specific* intended audience for the subject matter included on an SNS profile. Indeed, changes to an SNS privacy policy by the service itself can alter the publicity or privacy of one's profile or posts. As

⁹² Berg, Jessica. "Response to Open Peer Commentaries on "Surrogate Decision Making in the Internet Age"" *American Journal of Bioethics* 12.10 (2012): W1-W2.

⁹³ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 29.

a result, information that may be intended for a specific group may be uncovered by a wider-than-intended audience in a variety of ways.⁹⁴ In one instance, a surrogate who is looking for information on the patient for whom she is making medical decisions may perform a search engine query on (“google”) the patient and come across an SNS profile. In another instance, SNS profile information could come to light only when shared by a member of a small group of “unrestricted” contacts with whom the subject has previously chosen to share information. The informal electronic platform of SNS, combined with the fact that patients are unlikely to foresee the possibility of their SNS profile’s use for purposes of surrogate decision-making, creates an environment that potentially leads to a misleading view of their personhood and a distorted view of their values when that information is applied in the context of a serious issue. As a result, great care must be given to ascertain the context and tone of the material presented.

Moreover, one may consider how this new medium for publishing—and discovering—information may expose the patient to an invasion of privacy. Consider a scenario where a 23-year-old male college student is on life support and his parents are his surrogate decision-makers. The parents raised their son in a strict conservative Christian home and to their knowledge, he shares their beliefs. All of his friends from college know him to be an outspoken atheist and gay-rights activist who plans on moving in with his boyfriend shortly after graduation. All of this is unknown to his parents. On his Facebook profile, the young man “shares” and comments on numerous articles advocating marriage equality and a strong distaste for the beliefs of his parents

⁹⁴ As an example, Twitter currently allows its users to restrict posts to one’s “followers”, or make all posts public. However, a single change in the user’s settings may derestrict all previous posts that may never have been intended for public consumption, effectively increasing availability from a select few to the entire network of users.

on the Christian right. His profile photographs also document his romantic relationships and attendance at various gay pride events. In light of the stark differences in values between the young man and his parents, it may seem that the information garnered from SNS could be very relevant to his wishes for medical care. Nonetheless, the revelation of this information to his parents could be devastating to the young man, should he recover from his condition and find himself in a situation where information he would have otherwise gone to great lengths to avoid revealing to his parents is now freely shared.

A similar case could be imagined regarding a husband encouraged to log into his wife's SNS profile and view her postings for more information about her. Aside from legal implications, possible information security issues and fraud that could occur, the husband may also find that his wife is having an extra-marital affair—something which may compromise his ability or desire to act in good faith as her surrogate. The possible defense and justification for the use of SNS in this case, despite the aforementioned possible problems, is that this information *could* have come to light in more traditional, non-electronic means, possibly indicating that electronic information gives rise to many of the same concerns as other informational sources. Still, there is an ambiguity concerning the public or private realm of SNS that can vary largely from person to person and may influence the intended audience, the level of privacy which may need to be protected, and the way in which this information may be recovered or received.

Perhaps the most concerning aspect of employing SNS as informational sources for surrogate decision-making comes out of recent studies of data mining on SNS services. Recent efforts in data mining on SNS have yielded information from which outside companies may extrapolate statistical generalizations about individuals based on an aggregation of otherwise

disconnected activity. Such data can be collected from “liking” an article, saved searches, keystroke logging, or preferences related to advertising click-through. Each of these data points is important for SNS, and though rarely made public, could be made available in the future.

To be clear, content created by an individual on an SNS profile and statistical generalizations about individuals through data mining on SNS are very different and should be recognized as such for a number of reasons. (1) Generalizations brought about through data mining are removed in degree from the individual. Information extrapolated in the data mining process is independent of any information directly revealed by the individual, and is exactly what it claims to be—a statistical generalization based on keystrokes or advertisement click-through similarities between an individual and studied groups of people. Generalizations from data mining are removed significantly from the content of the profile of the individual being analyzed and are interpretive about an individual independent of any consideration for the dynamic nature and nuances of personhood. For generalizations in the pursuit of better, more “personal” advertising, it is acceptable to risk that a supposedly well-received advertisement be either rejected or ignored as the stakes are not nearly as high as they might be in the case of medical decision-making. (2) Information resulting from data mining, as opposed to created content on an SNS lacks even the possibility of intentionality on the part of the individual user. As discussed above, profile information found on SNS may vary in relevance and consistency when being examined for use in medical decision-making, but on some basic level, there is intention on the part of the individual to disperse information to some (even a select) audience. Whatever is “posted” or added to an SNS profile by a user is intentionally created—even in the case of online personas. At some point, the user was intending to portray himself, his values or interests in a specific way. In data mining, there can be no intention on the part of the user to portray

himself in a particular way. Records of keystrokes, advertisement click-through and similar data points cannot be reliably attributed to core values of personhood. As mentioned above, generalizations from data mining involve interpretation of an individual's identity totally independent of any meaningful *or* intentional content.

Most recently, the New York Times published an article on a recent study co-authored by a representative from Facebook and a researcher from Cornell University. The study compared the number of shared Facebook "friends" between romantic partners and has been able to successfully statistically predict the success or failure of a relationship, and when the relationships destined for failure are likely to end.⁹⁵ These examples of research present the clearest opportunity for gross abuse and the application of misinformation. In the recent article, "Personality and Patterns in Facebook Usage," the authors attempt to establish a correlation between individual's personality traits and "features of Facebook profiles." They claim to "then show how multivariate regression allows prediction of the personality traits of an individual user given their Facebook profile."⁹⁶ One of the authors, Cambridge University Professor Michal Kosinski points out both the value and concerns of this feature:

"The important point is that, on one hand, it is good that people's behavior is predictable because it means Facebook can suggest very good stories on your news feed...But what is

⁹⁵ Lohr, Steve. "Researchers Draw Romantic Insights from Maps of Facebook Networks." *The New York Times Bits Blog*. New York Times Company, 28 Oct. 2013. Web. 15 Feb. 2014.

⁹⁶ Bachrach, Yoram, Michal Kosinski, Thore Graepel, Pushmeet Kohli, and David Stillwell. "Personality and Patterns of Facebook Usage." *Proceedings: WebSci '12* (2012): 24-32. Microsoft. Web. 06 Apr. 2013.

shocking is that you can use the same data to predict your political views or your sexual orientation. This is something most people don't realize you can do.”⁹⁷

As Kosinski points out, this method of gathering information is excellent for advertisers looking to cater most directly to each user's experience and interests. However, claims to such reliable predictability and information that is supposedly highly accurate could lead to sweeping assumptions about values of people or patients which may not, in fact, be true. The article claims that without *any* direct revelation, an individual's political persuasion, religious affiliation, IQ level and sexual orientation could be determined with a near 80-90% accuracy in each of these factors.⁹⁸ One could imagine a circumstance in which a person is predicted to be heterosexual, a Christian and Republican. Based on those predictions, one might assume that in following the supposed views affiliated with each of these groups it would be wise to preserve life at all costs—an ideology often supported by these groups, but something that may not translate to the individual. Perhaps predictions like what the aforementioned article attempts to provide may be helpful in a case where there is no surrogate or other information available. However, the reduction of the individual to mere—albeit, often accurate—predictions seems to ignore the dynamic nature of personhood and what that may mean when considering decisions that mark the difference between life and death. Nonetheless, when such information becomes more readily available to the public and possibly to medical professionals, surrogates, ethicists, health care

⁹⁷ Halliday, Josh. "Facebook Users Unwittingly Revealing Intimate Secrets, Study Finds." *The Guardian*. Guardian News and Media, 12 Mar. 2013. Web. 12 Mar. 2013.

⁹⁸ *Ibid.*

teams and judges must carefully consider the information brought to light—what it may mean for patients when they regain consciousness or how it may influence their life or death.

3.2 THE CLINICAL DILEMMA AND POSSIBILITIES FOR FUTURE CONSIDERATION

The endeavor to use SNS as informational sources for surrogate decision-making in any context gives rise to great dilemmas with regard to its application. As previously mentioned, at present there is no reported use of SNS as an informational source for surrogate decision-making in practice and no documented use of SNS in health law in the United States. If a clinical team is in need of information regarding the identity of an unknown patient, it is unclear if the hospital should ever suggest the use of information from SNS in order to uncover the identity of a patient and find a surrogate via that avenue. Perhaps that question might be addressed more constructively outside the scope of this project, in a conversation about the law, identity and social media—for reasons more far-reaching than identification for medical purposes. Furthermore, it is unclear who ought to be tasked with conducting the search for information on SNS. In the future, this may be able to be done with the help of features like facial recognition technology, if local law enforcement were to attempt to identify a patient upon hospital drop-off or admission. A significant logistical concern would be around the manner in which information was sought or retrieved from social network spheres.

Regarding already established surrogate decision-makers, because of limited resources, supportive services and the current lack of known effectiveness of the use of SNS information, it

is unclear whether the hospital or health care team should ever suggest the use of information from SNS in order to find a surrogate or aid an established surrogate. This might be addressed more fully by individual care teams on a case-by-case basis according to the sources of information they may already recommend to families or surrogates, if they may recommend any at all, through medical ethics consultation, etc. Another important consideration is the significant burden which would be placed on the hospital or care team, should they become responsible for the suggestion or the support of such an endeavor on a regular basis. Perhaps it would be a more manageable undertaking for a well-developed medical ethics program, but few hospitals and medical centers provide those supportive resources regularly for clinical staff and surrogates.

An additional difficulty is the absence of policies, or a suggested standard of practice in medical literature regarding the use of SNS (or even social media generally) in surrogate decision-making. This may simply be a temporary problem of time and a matter of more discussion on the issue. We may see more social media policies and standards of practice arising in future literature. Additionally, many situations which might be helpful examples for case reviews may be handled on a case-by-case basis and only very select scenarios may be recorded in case studies and shared with wider audiences. Moreover, cases involving the use of SNS as informational sources for establishing surrogate decision-makers or for the surrogates themselves, are likely to be few and far between. The creation of a collection of cases in which SNS data is used in surrogate decision-making would be a valuable resource for the determination of the helpfulness of using SNS. It would be helpful for further information regarding the unforeseen ramifications of using information from SNS in this way and to inform medical professionals on how to best use the information to serve patients and families well. Furthermore, it would also be a great resource for eventual standard operating procedures for

using information from SNS in a clinical environment. This body of literature would include articles similar to those already written that offer examples of appropriate application and evidence of successful implementation. It should also include suggestions for the categorization of applicable scenarios, which has been suggested above and provide up-to-date context for decision-making using SNS in the imminently evolving landscape of practice. A more significant collection of literature on this topic might give rise to hospital and medical center-wide policies identifying (1) to what degree the provider can suggest and encourage SNS as a resource for surrogate decision-making. These policies would need to be born out of, and include consideration of local laws and policies regarding the legal standing of information taken from SNS as well as an assessment of the providers' available resources to encourage and support the additional exploration. (2) The policies regarding the use of SNS would need to provide a basic action plan for controlling and possibly containing the revelation of sensitive information. A consideration of possible regulations or restrictions on the use of SNS would be helpful in order to protect patient privacy if a hospital were to recommend the incorporation of information gleaned from SNS into the surrogate decision-making process. Ultimately, because potential policies defining standards of practice will need to be in accordance with local and statewide laws, a future established general consensus and practice may vary widely even within the same country.

3.2.1 Future Research Questions

Another constructive avenue for future consideration is gathering additional information about (1) social media and its relationship to identity as well as (2) more substantive information

regarding the manner in which people use social media—why it is used, how it is used, and what people hope to get out of the experience. There has been only basic research done, mentioned above, which seeks to better understand the relationship between the individual and the translation of identity to the virtual realm. However, little is known to definitively understand the nuances of interaction with relatively new virtual platforms.⁹⁹ Additionally, it will be helpful if future inquiry is able to categorize and explain data and information obtained from SNS and other social media, in order to help describe the terms of engagement between the user and the site. Some specific research questions may include:

Regarding Social Media and Identity

1. Does the translation of identity from individual to social media services frequently represent the individual for whom the profile is created in an authentic way?
2. If there are variations in the degree to which identities are authentically translated to SNS profiles, are there specific aspects of profiles that are more likely to authentically represent the personhood of the authors?
3. Are there aspects of profiles that frequently do not authentically represent the personhood of their authors?
4. What is the frequency with which online personas are used in SNS profiles?
5. Are there any signs indicative of the presence of a persona in an SNS profile such that if it is being used for information about a patient, one would know to use caution

⁹⁹ Stark, Meredith, and Joseph J. Fins. "The Self, Social Media, and Social Construction." *American Journal of Bioethics* 12.10 (2012): 38-39.

when applying the information to surrogate decision-making or to seek additional information to verify the legitimacy of the content?

These questions may be addressed through interviews with avid and occasional users to record their subjective opinions on whether their SNS profile accurately represents their personhood. These questions could also be addressed by asking close and more distant friends or acquaintances about their opinions of whether or not an SNS profile authentically portrays the individual whom they know outside of the social media realm. Interviews and questionnaires are qualitative and are likely to provide some imperfect answers to these questions. For example, an individual may perpetuate an adopted persona in an interview on the topic, which may not be recognized as a persona until the individual is in crisis. Furthermore, even close friends or other familiar acquaintances may be unable to detect the authenticity, lack of authenticity or aspects of the profile which may include both authentic and inauthentic statements and characterizations in order to yield definitive answers.

Regarding the Use of SNS

1. What are users' relationship with SNS? Is SNS a means to an end (e.g. SNS as a means to self-promotion into a popular group) or is it an outlet for self-expression?
What is the motivation for use?
2. Are there trends in casual or avid use that may aid in determining the expected volume or relevance of information?

Though the addition of information on the questions above would be helpful in better understanding what information from SNS means and how we can use it, there will still be a great deal of consideration needed to fruitfully employ information which may be uncovered.

3.2.2 Recommendations for Future Application

I expect that the responsibility for the exploration of the use of information from SNS and its application to the surrogate decision-making process may differ greatly depending on the complexities of a given situation. What I would suggest for one scenario would possibly be something I would advise against in another, even in thinking about aforementioned hypothetical cases. This makes a discussion of “piloting” this practice and assigning responsibility for the retrieval or use of this information very difficult. In an effort to provide some general guidance on how this process should be undertaken, I am prepared to make cautious suggestions about the responsibilities involved for the retrieval and use of SNS information in surrogate decision-making for the categories of scenarios I have discussed above: (1) cases where SNS might be used to discover a patient’s identity in order to determine a surrogate, (2) cases where a surrogate wishes to obtain more information about a patient in the hope of most faithfully executing decisions in accordance with the patient’s values and (3) cases where SNS is used as evidence of conflicting values on the part of the patient and may aid in conflict resolution.

In the first group of cases, where SNS might be used to discover a patient’s identity in order to determine a surrogate, I propose that the responsibility of uncovering this information should be shared by law enforcement, an ethics committee and a patient’s physician or broader care team. I want to affirm how strongly I suggest the engagement of law enforcement in these cases for two reasons: (1) Law enforcement has significant resources and training in uncovering information about citizens and in verifying the legitimacy of information. In cases where patient’s identities are unknown, other tools such as fingerprint databases and tattoo identification or documentation resources available to law enforcement may also play a role in

determining the identity of a patient. Queries of SNS and use of facial recognition software afforded on those sites may aid significantly in that process as well. (2) Such methods of inquiry are almost entirely outside the scope of expertise for clinicians, allied health professionals or members of an ethics committee. In sensitive matters such as the ones described here, I would advise an appeal to the qualifications, expertise and training of law enforcement personnel.

I propose the shared responsibility between an ethics committee and a clinical care team when considering the relevance of discovered information or when using SNS as an informational source. At this point, an ethics committee should deliberate over the information, advise if they should or how they might disclose information to a potential surrogate, or propose a treatment plan alongside the advice of the patient's care team. Additionally, the ethics committee might choose to consult with the hospital or medical center's legal counsel if necessary, or make other decisions about the necessity of additional information and how to move forward with a specific situation. The patient's physician and broader care team should be engaged to provide information concerning reasonable expectations for recovery, quality of life or any other factors that may be relevant in making decisions for a patient. This practice should be piloted, documented and evaluated based on its helpfulness and contribution to the successful determination of a surrogate, as well as its helpfulness to the decision-making process.

In cases where a surrogate wishes to obtain more information about a patient in the hope of executing decisions in accordance with the patient's values, I suggest that this responsibility be shared between the surrogate, the medical team providing the care to the patient and an ethics committee or medical ethics service. When providing medical ethics consultation to a surrogate who wishes to obtain more information about a patient for whom she will make decisions, it is appropriate for the ethics committee to suggest SNS as a possible informational source. (1) In

ethics consultation, if a surrogate voices a desire for additional information about a patient's wishes, it is not inappropriate for ethicists to encourage the pursuit and incorporation of information from other, more traditional sources such as friends or family members, other material written by the patient, or the consultation of religious texts that were meaningful to the patient. In the same way, I propose that those providing the consultation can (and should in some cases) suggest the exploration and consideration of information from SNS. Note that this suggestion falls directly in line with what has been previously argued about the employment of information from SNS up to this point, specifically that SNS be treated much like other informational sources and be subject to similar scrutiny concerning legitimacy, cogency, relevance and authenticity.¹⁰⁰ (2) Furthermore, I suggest that the surrogate should bear some responsibility in obtaining and evaluating information gleaned from SNS. Practically, the surrogate may have exclusive access to SNS information in the case of a publically "locked" or partially secured SNS profile. This exclusive access may be similar in the case of other sources of information as well (diaries or journals, etc.) where it would be appropriate for the surrogate to furnish that information and to introduce it to the decision-making process. Moreover, it is the responsibility of the surrogate to make decisions for the patient and that responsibility extends to informing oneself about the patient's values so as to make decisions in accordance with those values, insofar as they can be discovered.¹⁰¹

¹⁰⁰ Berg, Jessica. "Surrogate Decision Making in the Internet Age." *American Journal of Bioethics* 12.10 (2012): 31.

¹⁰¹ Buchanan, Allen E., and Dan W. Brock. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge UP, 1990. 190. Print.

After information from SNS has been introduced by the surrogate, either at the suggestion of those providing ethics consultation or at the surrogate's initiative, I believe it is the responsibility of the clinical care team and those providing ethics consultation to provide guidance to the surrogate in how to use the SNS information (as well as other relevant information) to make appropriate medical decisions. I suggest that this process also be piloted before wide application in clinical settings. While I have argued that employing the use of SNS as informational sources will be helpful in some cases, not all negative (possibly far-reaching) effects of the use of SNS information can be predicted. Nonetheless, piloting the use of SNS as informational sources in a small number of cases may help to either guide application in a broader number of cases or reveal hazards of such application that cannot be predicted prior to even limited experimental implementation.

Pilot programs may be evaluated for effectiveness in a number of ways:

1. Should a previously incompetent patient for whom SNS was consulted in the decision-making process regain competence at a later time, he could be interviewed for his opinions on whether or not the information gleaned from SNS, which may have been used to make decisions for him, was representative of his authentic values.
2. Surrogates could be interviewed for their opinions on whether or not they believed the information from SNS was helpful in making the required decisions.
3. Both surrogates and members of the health care team could be interviewed about the degree to which they were satisfied or unsatisfied with the support structures in place that may or may not have played a role in the suggestion or facilitation of the use of SNS in the decision-making process. This question could be somewhat problematic as it may give rise to more general feedback on the support given to surrogates during

the decision-making process more generally—but may also yield information specific to the experience with information from SNS.

4. Pilot programs can be evaluated by the accessibility of the methods of discovery of information from SNS. If surrogates or law enforcement struggle to obtain information from SNS, it may be less useful to attempt a broader application of the use of SNS in the surrogate decision-making process.
5. A pilot program could be evaluated for the impact of the use of SNS on hospital or medical center resources. Is the implementation more burdensome in terms of time and other resources than helpful? Are surrogates able to make equally satisfactory, but more efficient decisions based on the new source of information?

Though these suggested methods of evaluation are largely qualitative and may prove vulnerable to unclear or biased information based on the nature of qualitative research, these difficulties mirror larger difficulties of surrogate decision-making generally, namely that clear indisputable evidence of “good” decisions is difficult, if not impossible to determine. Questions like these seek to aid the decision-making process and push it further toward decision-making in good faith with the information available.

In the final suggested application, where SNS may be used as evidence of conflicting values on the part of the patient and may aid in conflict resolution, I advise against actively piloting the use of SNS in these scenarios. I am doubtful that in cases where there are disagreements among surrogates or between a surrogate and another individual about the wishes of a patient, the mere introduction of SNS (or other sources of information) as a possible source of clarification would result in helpful discussion. Rather, I suggest that in cases where there is disagreement between decision makers, the information that has already been presented in

support of conflicting values be evaluated before other sources of information are suggested. I would expect that both parties would present qualifying evidence for their claims about the patient's values or wishes and it may be possible that a solution is found in existing material.

However, in cases where information from SNS is introduced independent of any recommendations and presented as evidence of a claim by one of the disagreeing parties, it would be helpful and reasonable to engage the material at that time. In such cases, I propose that the decision-making process and outcome should be documented for review and evaluation for usefulness as similar situations may continue to arise in the future. Ultimately, in cases where there is a disagreement about the desires of a patient, I would advise that the disagreement be addressed by the clinical care team and possibly also with ethics consultation. I do not think that SNS should necessarily be suggested for use in these cases, which is why I would not suggest piloting this effort *per se*, largely because conflicts themselves should not be manufactured or exacerbated for pilot. In cases where information from SNS is brought into the discussion by one of the disagreeing parties, it should be examined and evaluated in the same manner as other informational sources. I think the use of SNS as evidence in the cases of conflict should be addressed on a case-by-case basis and be reviewed for helpfulness or hazardousness once there have been a number of cases in which it has been employed.

4.0 CONCLUSION

The conversation regarding the use of SNS as informational sources for surrogate decision-making is extremely complicated, sitting at the crossroads between the practice of medicine and law. The legal aspects of the use of SNS are further complicated both by what little has been written regarding the use information from SNS generally and by the paucity of legal discourse on the matter specifically. Additionally, the nature of surrogate decision-making in light of potentially very complicated scenarios may engage a wide variety of interested parties beyond clinicians and those with legal expertise. Rather, situations may need to take into account the concern of those interested in medical ethics or other medical humanities as well as the interests and experiences of patients, families and surrogates as they engage in a difficult task. There are many circumstances in which the use of SNS as informational sources for surrogate decision-making more easily fits into narratives which resemble the common use of other, more well-accepted informational sources for surrogate decision-making, but many may fall outside of such a “clear cut” scenario. Additionally, though information from SNS may be subject to many of the similar concerns surrounding other sources of information which surrogates may draw on, there are some imaginable situations in which the information used could be especially hazardous. The information gleaned from SNS should be rigorously reviewed for legitimacy, cogency, relevance and authenticity. Consistency in the findings with other aspects of a patient’s life as well as its

applicability to the situation a hand may be other relevant factors for consideration. Indeed, the practice should be considered and undertaken with extreme caution.

It is unknown whether the practice of using SNS as informational sources for surrogate decision-making will be employed in practice, and if so, to what degree. However with the wide acceptability of the use of information from SNS in other areas, particularly with regard to the trending treatment in law and local or federal policies regarding social media generally, the discussion, while perhaps premature, is not irrelevant. Moreover, the sober discussion of the use of information from SNS in this way prior to its implementation or clinical exploration may provide guidance and prove useful when situations arise where its use comes up organically. For this reason, suggested manners in which the complex nature of surrogate decision-making may evolve, along with potential frameworks in which possible new information from SNS could be dealt with may aid in the service and care of incapacitated patients, should their SNS profiles be consulted.

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